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ABSTRACT

Acquired Immune Deficiency Syndrome (AIDS) is a potent and a present danger for teenagers, casting a dark shadow over their lives now and in the future. A small, but significant, number of teenagers will develop Human Immune Virus (HIV)-related illness before they turn 20; a far greater number will become infected with the virus during adolescence. More importantly many teenagers will adopt patterns of sexual behavior and drug use that will continue to put them at risk for HIV throughout their adult lives. To protect youth the need for effective HIV prevention education must be addressed. Successful prevention programs and needed clinical care will require financing. Even in this time of fiscal austerity the provision of funds to create and maintain such interventions cannot be foregone. (Ten recommendations for the State of New York are listed. Among them are: (1) a requirement that every school provide explicit and culturally and developmentally appropriate education on HIV; (2) all programs that serve adolescents disconnected from schools must provide HIV prevention education; (3) community-based comprehensive programs for those adolescents whose behaviors place them at highest risk of acquiring HIV infection and for those already infected should be established; and (4) a private/public partnership to develop and conduct a sustained, consistent HIV prevention education campaign targeting teenagers should be initiated by the Governor.) (ABL)

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ILLUSIONS OF IMMORTALITY
The Confrontation of Adolescence and AIDS

A Report to the
New York State AIDS Advisory Council
From the Ad Hoc Committee on Adolescents and HIV
January 1991

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EXECUTIVE SUMMARY

On the basis of six months of testimony and deliberations, the New York State AIDS Advisory Council Ad Hoc Committee on Adolescents and HIV has concluded that HIV presents one of the gravest threats to the lives of adolescents throughout New York State. AIDS is a potent and a present danger for our teens, casting a dark shadow over their lives now and in the future. A small, but significant, number of teens will develop HIV-related illness before they turn twenty; a far greater number, however, will become infected with the virus during adolescence, to become symptomatic as much as a decade later. Most importantly, many teens will adopt patterns of sexual behavior and drug use that will continue to put them at risk for HIV throughout their adult lives. To protect our youth, we must address the need for effective HIV prevention education. Successful prevention programs and needed clinical care will require financing. Even in this time of fiscal austerity, we cannot forego providing the funds necessary to create and maintain such interventions. The recommendations that follow require a minimum of $16 million in new monies for 1991, and a commitment to ongoing annual support.

However, the long-term economic and social costs of abandoning our youth demand that New York State devote these barely adequate resources to these efforts. Furthermore, as the Committee has fashioned these recommendations to maximize all possible sources of federal reimbursement, the actual cost to New York State will be limited.

RECOMMENDATIONS

1. The New York State Department of Education and the New York City Board of Education should require that every school provide ongoing, frank, explicit and culturally and developmentally appropriate education on HIV infection, transmission and prevention, as part of a comprehensive program of health education and life skills training, to all children in all grades. These programs should integrate assistance from and develop outreach to parents, the community, and adolescents themselves. Schools and their supervisory agencies should report to the Governor yearly through the New York State Department of Health on the content of these programs and on their evaluation, implementation and monitoring.

2. The Governor should ensure that all programs that serve adolescents who are disconnected from schools must provide HIV prevention education as an integrated part of their service delivery. The AIDS Institute should develop appropriate HIV

prevention education and provide trainers for all staff in programs that serve adolescents.

3. New York State should establish community-based comprehensive programs for those adolescents whose behaviors place them at highest risk of acquiring HIV infection, and for those adolescents who are already infected. These programs should provide developmentally appropriate HIV prevention education, confidential medical care, social services, and counselling. Programs should be designed so that adolescents can gain access to all programs and services on their own initiative and consent. New York State should allocate $12 million in 1991 to these programs.

4. New York State should allocate $2 million in 1991 to develop special programs targeted to those adolescents under the jurisdiction of the Division for Youth (DFY) and those adolescents who are "out-of-home" or "on the street."

5. New York State should develop adolescent-specific substance abuse treatment programs to provide access for adolescent substance abusers and substance abusing pregnant young women.

6. We make the following major recommendations for the reform of Medicaid:

a. New York State should immediately identify and review Medicaid financial eligibility and documentation requirements, modifying them as necessary to facilitate enrollment of eligible adolescents.

b. The State should immediately establish additional convenient sites for eligibility determinations and application assistance programs at primary care settings serving adolescents at risk for or infected with HIV.

c. Presumptive eligibility for HIV-infected adolescents should be provided out of state funds.

7. The New York State Department of Health should allocate $1 million in 1991 to train providers of services and counselors to adolescents in the skills necessary to counsel adolescents about HIV testing in order to increase identification of HIV-infected individuals in this age group. These counselors must be knowledgeable about pre- and post-test counseling and referrals for care and services.

8. New York State should allocate a minimum of $500,000 per year to establish an "Adolescent AIDS Research Center" to collect epidemiological information necessary to improve our understanding and enhance our ability to intercept this epidemic and to gather data on the characteristics of the disease in

adolescents, on adolescent behaviors which place them at risk, and on patterns of transmission in this age group.

9. The Governor should initiate a private/public partnership with the business, media and advertising communities to develop and conduct a sustained, consistent HIV prevention education campaign targeting teens.

10. The Governor should allocate $500,000 in 1991 to create an Office of Adolescent Services directed to meld categorical funding streams into comprehensive programs, maximize funds available under matching and reimbursement formula, and coordinate complementary and overlapping agency responsibility for adolescents.

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ILLUSIONS OF IMMORTALITY
The Confrontation of Adolescence and AIDS

A report to the
New York State AIDS Advisory Council
From the Ad Hoc Committee on Adolescents and HIV

I. Introduction

This report is intended to sound an alarm and to alert society to the dire consequences for our children and for ourselves that are sure to follow if the incidence and prevalence of HIV infection in adolescents continues to rise. The Ad Hoc Committee on Adolescents and HIV, convened by the New York State AIDS Advisory Council to analyze the dimension of the threat posed by HIV to adolescents, is convinced that we face a grave epidemic. While the number of cases of AIDS among adolescents is still small (76 cases among teenagers aged 13 to 19 in New York State reported as of October 31, 1990), it is but the tip of an iceberg and is itself clearly a product of underreporting. The 5646 cases already reported in New York State as of October 31, 1990, among young adults aged 20 to 29 represent in large part persons infected during adolescence.

Compassion requires that we provide medical care and treatment, housing and psychosocial supports for those teens already infected; what we now provide is shamefully inadequate. Self-interest argues for effective education to prevent transmission of the virus to greater numbers of adolescents and

from those infected to other adolescents and adults; what we now do is woefully ineffective.

The reality is bleak. New York City has more cases of AIDS among adolescents than any other city. A study by the Alan Guttmacher Institute has found that 80% of the city's teenagers are sexually active by age 19; all of these young people are potentially at risk of infection. Although the incidence of AIDS is highest in New York City and in other urban areas, cases have been reported from all counties in New York State. All adolescents, urban or rural, upstate or downstate, are at risk. These stark facts frame this report. The young people of this state are becoming infected with HIV. If we don't stop the transmission of the virus even larger numbers will sicken and die. While becoming sick, they may infect others, and in addition may transmit the infection vertically to newborns. This is an unacceptable future.

The opening months of 1991 are not a propitious time to argue for new programs and new funding. This is particularly true for long-term difficult problems that preclude a quick fix. Since adolescents traditionally lack access to medical care and to services, new programs must be an essential component in any effort to reach this population. Moreover, these costs dwindle in comparison to the horrendous costs to our society of abandoning our youth to the devastation of HIV infection.

There are even more daunting obstacles than money to devising effective strategies to combat the spread of HIV

infection among teenagers. Successful programs will require imagination and courage. They must be blunt and straightforward about sex and drugs. They must acknowledge that most adolescents are sexually active and that many use drugs, while at the same time giving teens self-confidence and strategies to resist both drug use and pressure to engage in sexual experiences they do not want. Programs must also recognize and respond to the disorder and deprivation which surround many of these young lives, especially when they are poor. They must confront the ambivalence of society about many teen behaviors and the unwillingness of many adults to face the present reality of adolescence. Effective programs must reflect and respond to reality and be able to pierce the "veil of secrecy" that surrounds this epidemic.

Explicit prevention education about HIV and its patterns of transmission that results in changed behavior is the only vaccine we have against the spread of this epidemic. Developmentally appropriate clear and blunt teaching about sex and drugs must be the foundation of all educational efforts.

Finally, adolescents themselves may pose one of the most forbidding obstacles to combatting the spread of HIV in this population. The developmental characteristics of adolescence, including life style experimentation, perceptions of immortality, and limitations of judgment, complicate the tasks of shaping appropriate programs. The threat of HIV infection, not sufficiently imminent to adults, fades into the distance for many

teens and is dwarfed in their minds by the urgency of everyday concerns and the process of maturation. Many adolescents have learned to see AIDS as a disease of gay white men and intravenous drug users, and use these myths to deny their own risk behavior. For street kids and others at highest risk of infection, fears of the virus are overwhelmed by more immediate needs -- food, shelter, care, or a means of obtaining money for drugs -- that take precedence over the possibility of becoming ill some ten years from now.

Adolescence is the last time we can use formal education to affect risk associated behaviors that will put individuals and their sexual and drug sharing partners at risk, both now and in the future.

II. Age

Adolescence is an ill-defined term whose upper and lower limits are not set by firm chronological boundaries but by markers of emotional and cognitive development. Adolescence begins as a child initiates the growth and separation process that will lead ultimately to independent adult living; it ends when the child's emotional maturity and cognitive skills have developed to the point where she can support the degree of separation necessary for independence. These markers or stages of development vary in individuals, and cannot always be correlated with chronological age. Nonetheless, this report requires a working definition.

In formulating its recommendations and report, the Committee has elected to extend the age boundaries of adolescence beyond that period from ages 13 to 18, commonly used to characterize adolescence, to include all youth aged 10 to 24. For some young people, adolescence may not begin until age 13 and may be completed by age 18, the legal age of majority. However, for many children, and particularly for those who have adult responsibilities thrust upon them at an early age, or who lack firm adult guidance, adolescence can begin as early as age 10. In addition, the maturation process may not be completed by legal adulthood at age 18; for many adolescents, whether in or out of college, the period between 18 and 24 is often one of continuing maturation, cognitive development and self-definition.

It is equally important in addressing the issues of sexuality, sexual development and substance abuse not to overlook children under age 13. By age 13, many children have developed a firm concept of sexuality, and, indeed, are likely to be involved in some degree of sexual exploration. A small but non-trivial number of youngsters are engaged in sexual intercourse. In addition, especially in some neighborhoods, ten year olds are also likely to encounter drug use. Thus, experimentation with and attitudes toward drugs and sexuality may both begin by age 10. If we wish to prevent the establishment of behaviors that can put children at risk throughout their lives, we must tackle these issues at the earliest possible developmentally appropriate moment.

While developmental issues have led the Committee to focus on youth between the ages of 10 and 18, specific practical issues require the extension of the boundary to age 24. Private insurance often provides coverage for dependent youth through this age. This possibility of dependent coverage creates a group which may be limited in its ability to gain independent access to medical care. This lack of access to medical care presents an enormous obstacle to stemming the infection in this group and argues for its inclusion for the purposes of this report.

III. Characteristics of Adolescents

Adolescence is a time for experimentation with various behaviors, life styles, experiences, peer groups and identities. For some, it is also a time of passionate commitment to political issues, to idealism or to materialism. It is a time to discover personal strengths and test out approaches to the world. For most youngsters in 1990, as noted above, adolescence involves sexual investigation; for some it involves experimentation with drugs. This process of choosing among identities and behaviors sets the ground for adult personality. Unfortunately, this very process of maturation may put adolescents at risk for infection.

HIV infection has not changed what adolescents do; it has, however, changed the stakes. If sexual relationships and drug sharing conduct involve HIV-infected persons, typical behavior and experimentation become life threatening.

This is a difficult message for adults to comprehend and is doubly hard to sell to adolescents. For developmental reasons, most adolescents see themselves as invulnerable if not immortal. Dangers or warnings are "for others," not for them. Many adolescents who engage in high risk behavior and who may already have been exposed to HIV infection, or who may in fact be infected, will never perceive themselves as being at risk.

Historically, normal adolescent behavior, including trials of new identity and even exaggerated or abrasive attempts at detachment from parents, took place within coherent communities and more or less secure family structures. While this stable family and community life was never a norm experienced by all teens, it was certainly more than a well-accepted myth and probably reflected a fairly widespread reality. Stable communities and functioning families helped to set limits, define acceptable behavior, reinforce reality and guide adolescents toward self-protective actions.

Today fewer limits are set by family and community. As described by Dr. Mindy Fullilove, in poor urban neighborhoods, communities may be "shredded," a step beyond disorganization and decay. Society's message, as glimpsed in movies, television and advertising seems clear: sex is cool and money talks. Economic and social strains have weakened families, removing those guidelines and boundaries necessary to prevent young people from slipping over the edge as they experiment with dangers.

Adolescents are volatile and impressionable, inquisitive and courageous, with a strong sense of integrity and of the value of relationships, especially with peers. Their behavior, however, regularly puts them at risk for the transmission of HIV infection. What is particularly difficult to relay to this group, as well as to adults, is that it is the context as well as the content of behavior that puts them at risk; sexual intercourse without a condom with an infected person is dangerous.

The degree of social risk to which an adolescent is exposed results directly from the decisions he or she makes about engaging in high-risk behavior. The process of decision-making is poorly understood in adults, let alone in adolescents; the differences between adolescent male and female decision patterns are virtually unexplored. Most decision-making by adults, as well as by adolescents, is a mixture of information, analysis and emotion. A rational decision-making model, under which sequential steps lead to prudent decisions, has been the core of most social science analyses and the basis for many behavior modification programs. This model, however, largely reflects an abstraction rather than reality. We do know that an adolescent's decisions are likely to be made under conditions of high uncertainty, inexperience and strong emotion. Rational, abstract models do not apply under these conditions. In addition, as with all people, decisions come to be intertwined, intermingled and interdependent. This appears to be an accurate characterization

for all decisions; it most certainly applies, however, to decisions involving peer pressures, sexual identity and sexual and drug using behaviors.

Intellectual models assume that individuals opt for risk-averting behavior. Adolescents, who in their role as adolescents need to experiment and to court danger, may opt for risk-courting behavior. Risk-courting and risk-averting behaviors may also be defined differently by an adolescent and an adult. An adolescent girl may choose to engage in unprotected sexual intercourse in order to avoid the risk of losing her boyfriend. For adolescents, bucking the opinions and actions of peers <u>is</u> very threatening behavior.

In attempting to prevent and to treat HIV infection among adolescents, we must recognize that taking risks is inherent in this stage of life. Rather than attempting to force adolescents into protective courses of action that defy these processes of maturation and development, programs must be designed with understanding of the unique needs of this age group. If programs do not address the issues surrounding HIV within the developmental and cognitive capabilities of adolescents, they are likely to fail.

IV. <u>The Epidemiology of HIV Among Adolescents in New York State</u>

New York State and, in particular, New York City can easily be described as the epicenter of the epidemic of HIV in adolescents. As of March 1990, 20% of all reported cases of AIDS

among persons aged 13 to 21 in the United States were diagnosed in New York City. Dr. Karen Hein, an expert on adolescents and HIV, has suggested that New York City "may now be a crystal ball for the rest of the country," illustrating the likely impact of HIV on adolescents throughout the United States.

AIDS adolescent case data, however, has only limited value in demonstrating the true dimensions of the epidemic. As noted above, the number of reported cases of AIDS among both adolescents and those aged 20 to 29 points to a growing rate of HIV infection among adolescents. Given the eight to ten year delay between infection and development of symptoms, relatively few HIV-infected youth will present with full-blown AIDS during adolescence. Reported HIV prevalence data for adolescents may also be misleading because the obstacles that prevent adolescents from gaining access to health care limit the number of adolescents undergoing HIV testing. The lack of contact points with adolescents make blinded anonymous serosurveillance difficult. In addition, practitioners are not sufficiently aware of AIDS as a disease of adolescence; this decreases the likelihood of testing and increases the probability of underreporting of HIV infection in this age group.

New York State, New York City and the federal government have initiated studies of the rates of HIV infection, known as "serosurveys," among various subsets of high-risk adolescents. Studies carried out in New York City, admittedly of small samples of adolescents, have revealed relatively high seroprevalence rates:

2.2% for those under age 19 and 9.7% for those beyond age 19 at sexually transmitted disease (STD) clinics; 0.16% for males and 0.17% for females aged 17 to 19 applying for military service; 1.03% for women under 19 giving birth or terminating pregnancy; 6-8% for runaway and homeless youth at Covenant House's medical clinic.

By definition, many of these adolescents are at high risk of infection. Clients of STD clinics and adolescent mothers clearly have engaged in unprotected sexual activity; the rates of infection in these subpopulations warrant alarm.

Available data on HIV seroprevalence and HIV illness among adolescents and young adults provide a picture of the epidemic that differs from the epidemic among adults. The proportion of cases of AIDS among females is strikingly higher among adolescents than among adults; while the male to female ratio in New York City has been 5:1 among those individuals over age 24, it is only 3:1 among thirteen to twenty-four year olds. Heterosexual transmission appears to be substantially more common among adolescent women; among cases of AIDS nationwide, heterosexual transmission was cited as the source of infection for approximately half of cases among adolescent females (here aged 13 to 21), but for only 29% of cases of AIDS among adult women (over age 21). In New York City, young adult cases (20-24) are more likely to be either Black or Hispanic than are adult cases (36% and 32% compared to 33% and 25%) among those persons over age 24.

There are no reliable data on homosexual or homeless youth; however, gay adolescents, street kids, and those under the jurisdiction of the New York State Division for Youth (DFY) are of special concern. Stigmatization of homosexuality and fear of rejection may lead many gay youth to run away from home -- exposing them to increased dangers. Fear of stigmatization may lead to secrecy and denial, which may prevent adolescents experimenting with homosexual behavior from seeking out HIV prevention information or applying it to their own behaviors. Young gay men share their peers' feelings of immortality and may refuse to acknowledge their own risk of infection. Adolescent lesbians may use unprotected heterosexual intercourse as a means of denying their own sexual identity or may experiment in heterosexual activity with gay male peers. A gay adolescent, struggling with his sexual identity and fear of peer rejection, may be unmindful of precaution as he engages in clandestine sexual activity, often with adult males. Many street kids, runaways and those barely "in-home" support themselves through heterosexual and/or homosexual prostitution, compounding their risks. In addition, a substantial number of adolescents who will ultimately define themselves as heterosexual will engage in sexual experimentation with members of their same sex.

The New York State Division for Youth admits over 2000 youngsters per year, mainly from the state's urban centers, to its residential facilities. These teens are mainly poor, 58% have used drugs; 23% have serious alcohol problems, 16% have

committed sex offenses and 20% are the victims of sexual abuse. Virtually all are sexually active. Runaway and homeless programs supported by DFY serve over 30,000 teens annually in New York State, of whom some 50-75% admit involvement with drugs.

Among adolescents, as among heterosexual adults, intravenous drug use is a risk laden behavior. But among adolescents, IV drug use, although important as a route of transmission, may be secondary to transmission through high-risk sexual activity associated with the use of crack cocaine and other substances. Anecdotal evidence indicates that compulsive sexual behavior and prostitution for money or drugs both surround the use of crack cocaine.

We must recognize that all adolescents who are sexually active are at some risk for infection especially if they live in communities where seroprevalence is already high. In these areas, experimentation with either heterosexual or homosexual behavior may put adolescents at risk. We must not confuse the issue: behavior -- not community residence or other demographic characteristics -- places individuals, including adolescents, at risk. However, the greater the possibility that an adolescent's sexual or needle-sharing partner is infected, the greater the risk incurred by engaging in unprotected sex or needle-sharing. If the likelihood that potential partners are infected is significant, serial monogamy and other behaviors may be much riskier than generally acknowledged. Most importantly, the changing patterns of adolescent behaviors makes it particularly

difficult to determine degrees of risk as adolescents experiment with self-image and lifestyle.

Some adolescents may have been infected by HIV through perinatal transmission. Although it is unlikely that there are a substantial number of perinatally-infected adolescents at present, there is every reason to expect that this group will grow in future years. A recent report in the Lancet described the case of a twelve-year old girl who was shown to have been infected through perinatal transmission and who to date has remained asymptomatic. It has been estimated that some 1900 HIV-infected women give birth to children each year in New York State; 20-40% of the infants born to these mothers will be infected with HIV. While little is known of the natural history of HIV illness in children, it appears that a number of these children may survive at least into early adolescence. They will likely outlive their mothers and may thus join the ever growing numbers of orphans living in foster care or with members of their extended family.

There are two final routes by which adolescents may have been infected with HIV: exposure to blood and blood products, and sexual abuse. Blood and blood products no longer present a significant mode of transmission of HIV; however, we will continue to see cases of HIV illness and AIDS among adolescents exposed to the virus through transfusions, treatment for hemophilia, and other medical treatments carried out before HIV testing of all blood and blood products was implemented in 1985.

A substantial proportion of adolescent hemophiliacs who were treated with blood products prior to 1985 are infected with HIV.

Finally, some children may be infected through sexual abuse by adults. This may, indeed, be a substantial group although data are unavailable.

V. The Social Context

Teenagers are put at risk both by their own behavior and by the perilous environment in which they live. The onset of sexual behavior is far earlier today than it was in the past. Data recently published by the Alan Guttmacher Institute indicate that rates of sexual activity among adolescents continue to rise rapidly. Among adolescent girls surveyed in 1982, 32% of those aged 15 to 17 and 64% of those aged 18 to 19 reported that they had ever engaged in sexual intercourse. By 1988, fully 40% of younger girls and 74% of those in the older age group indicated that they had been sexually active. The report also noted that teenagers are now more likely to have multiple partners.

Little remains of the previously accepted, if rarely honored, boundary between premarital and marital sex. Most young people have a different sexual career than did their parents, one characterized by multiple partners in a pattern of serial monogamy.

Many kinds of substance use threaten adolescents. As noted previously, opiates and heroin both present dangers. But the use of more familiar intoxicating substances -- alcohol and marijuana

-- are also dangerous. Alcohol and sex can be a deadly combination for teens. Any drug use that serves to suppress social and personal inhibitions leads to an increase in unprotected sex, enhancing the possibility of infection.

Sexual experimentation and substance use are encouraged by the media. Television, movies, rock songs, advertising and music videos, all sell the glamour of money, sex and risk taking behavior while few or none of the adverse effects are shown.

While the social destabilization that shapes the lives of so many youngsters is beyond the scope of this report, certain important elements must be noted. The disintegration of families and neighborhoods is linked to a more profound, although most certainly associated phenomenon, the emergence of multi-generational poverty. This growth of entrenched poverty is accompanied by the widening gap between rich and poor, the increase in teen pregnancy, the decline in economic opportunity, the lure of high paying employment available in the illegal drug industry, and the fact that all of these catastrophes disproportionately affect poor communities and communities of color.

These declining economic and social opportunities may encourage adolescents to engage in precisely those behaviors that put them at risk. While we may not be able to alter these factors by any means short of a dramatic structural reform of society, we must recognize that they establish the context within which some adolescents make their decisions about their

behaviors and their lives. We can only reiterate that programs, to be effective, must address the reality of adolescents' lives.

VI. Adolescents and the Health Care System

Health care services must be an essential element of any strategy to contain the epidemic of HIV among adolescents. Those who are infected need monitoring and treatment. For adolescents, confidential health care and social services could provide an additional source of support to encourage testing and early detection of HIV infection. This is particularly important now that effective prophylaxis and early treatment are available. However, adolescents have long had a problematic relationship to the health care system and, in general, have suffered from the lack of access to medical care. There are legal, ethical and economic reasons for this state of relative neglect.

Legal obstacles emerge from the assumption that parents must consent to medical care for their children and adolescents. In the last decade and a half that assumption has been overtaken and largely overridden by events. Cases decided by the U.S. Supreme Court and by various state courts, congressional legislation and state statutes have now determined that adolescents, absent parental consent or supervision, have a right to family planning counseling, contraceptive information and contraception devices and prescriptions; a right to buy condoms; a right to receive medical care for sexually transmitted diseases and conditions related to sexual behavior; a right to alcohol and drug

treatment; a right to confidential care and treatment for pregnancy; and a limited right to abortion without parental consent (although in some states not without parental notification).

In addition to these specific rights, many of which are directly relevant to prevention of HIV infection, there are also customs of providing medical care. Most providers will provide confidential care for adolescents, especially when the adolescent is older (15 or more), the care is non-controversial and is clearly in the "best interest" of the child. This provision of service for the adolescent alone is further buttressed in New York by the AIDS Confidentiality Law which provides specifically that an adolescent may undergo HIV testing on the basis of his or her own consent. In addition, New York has variations of the "emancipated minor" and "mature minor" rules which permit some youngsters who are married, pregnant or who have borne a child, or who are truly independent of their parents to consent to care.

This Committee assumes that young people at risk for the transmission of HIV infection are capable under some combination of the factors listed above to consent to their own testing, diagnosis, care and treatment.

Whether this pattern of care provision is ethically appropriate is a separate matter. The fact that an adolescent can legally be counseled and tested for HIV infection on his or her own does not mean that care providers should see the adolescent as an isolated individual. Providers should strive to

ensure that there is an involved adult, whether a relative, friend or care provider, who can help this teen deal with the crisis of learning that he or she is infected with HIV or interpret the meaning of a negative test result. There are good reasons an adult should be involved with care plans and provision. Ideally, an adult would provide wise counsel, emotional support, a broader perspective and an ability to weigh the risk and benefit of any suggested intervention. But if no adult is available and services are necessary, youngsters should be permitted to consent on their own.

All providers who treat adolescents attempt to link them with their parents -- that is always the preferred care plan. But, sometimes, and often in the case of adolescents at risk for HIV transmission or infected with the virus, this alliance is neither feasible or desirable. Often the parents are a part of the problem and not the solution. Many young people at highest risk for HIV transmission have no parent or adult in their lives who is able to provide this support and counsel. Many adolescents have fled their homes out of fear or to escape a loveless setting. Some adolescents perceive their parents as abusive and dangerous; some parents are. A significant number of adolescents are so alienated and angry that a requirement of parental involvement will effectively drive them away from care.

There is no question that providers have enhanced ethical duties to and dilemmas about younger persons with no mature and involved adult in their lives. There is also no question,

however, that confrontation with these dilemmas is superior to excluding these young people "a priori" from care. In this, as in other matters involving adolescents and AIDS, we must work within the reality provided rather than rail against it.

Payment is often a major barrier to provision of care. Nationally, 14% of adolescents aged 10 to 18 and 26% of young adults aged 18 to 24 have no public or private health insurance. Among poor adolescents and young adults, who are more likely to live in high seroprevalence areas and thus to be at higher risk for HIV, the rates are even higher. Fully 31% of poor adolescents and 35% of poor young adults have no health insurance.

Virtually all adolescents and young adults who are privately insured receive coverage as dependents under their parents' individually purchased or group health insurance plans. As a result, their parents in effect control their dependent children's access to health care financing. Indeed, part of the reason, historically and now, for requiring parental consent is to secure parental financial liability for care provided.

In New York, any adolescent with family income below the federal poverty level is eligible for Medicaid, the largest source of public health financing for both pediatric and AIDS-related care nationally. Given the exceedingly high cost to both the state and local governments of caring for persons with AIDS, the federally-assisted Medicaid program represents one of the few sources of significant financial assistance for these patients

and is of particular importance. However, based on^^ lensive discussions with local providers of care to adolescents and young adults, we have reason to believe that New York's Medicaid coverage policies for adolescents may warrant particularly close scrutiny, at least for this sub-population. The potential problems fall into three major categories: 1) the financial criteria used to determine eligibility for benefits and the barriers created by having to prove one's eligibility for benefits, 2) the ease with which adolescents (particularly those who are HIV-infected and without family support and thus under extraordinary stress to begin with) can secure entry into the program, and 3) the absence of immediate coverage for those adolescents willing to brave the system and seek medical assistance.

1. Barriers created by financial eligibility criteria and eligibility-related proof.

New York is to be commended for not restricting Medicaid coverage (as do approximately 30 states) to certain sub-categories of poor children and youth, and for establishing enhanced Medicaid reimbursement rates for HIV-related care that address the disincentive of providing costly AIDS care. Nevertheless, the financial eligibility criteria themselves pose enormous burdens. Adolescents applying for Medicaid must prove that both their incomes and assets fall within allowable standards. Despite the fact that many of the adolescents

applying for benefits have virtually no income or assets, the task of proving the negative can be arduous. Moreover, even applicants who can prove their financial eligibility also must prove that they qualify on the basis of age, that they are citizens or aliens lawfully admitted for permanent residence in the U.S. and that they are residents of the state of New York. Studies repeatedly have shown that the vast majority of denials of applications under Medicaid in the case of families with children occur not because of applicants' failure to meet financial or other criteria but because they cannot comply with the program's stringent documentation requirements.

Even where an adolescent can muster the needed proof, certain methodologies used to determine Medicaid eligibility may work against the adolescent, particularly in the case of runaway and homeless youth. Financial methodologies used to determine Aid For Dependent Children (AFDC) eligibility normally are incorporated automatically into state Medicaid eligibility standards (because of the piggyback nature of the Medicaid program). One of these methodologies may classify runaway youth as only temporarily absent from their parent's homes, thereby requiring that all parental income be treated as, or "deemed," available to the adolescent.

A second potential eligibility problem concerns the requirement that applicants disclose all third party liability (TPL) to which they are entitled at the time of application. In the case of runaway youth, this "TPL" disclosure rule may compel

them to reveal themselves and their whereabouts to parents so that dependent private insurance benefits can be pursued.

Both of these requirements - - the deeming of parental income and disclosure of third party liability - - can create extremely serious practical and legal barriers in the case of otherwise eligible adolescents who are unwilling to, or afraid of, revealing their whereabouts to their parents. The barriers are costly, since they effectively preclude the establishment of Medicaid eligibility.

2. Barriers to Application

Like virtually all other Medicaid applicants, adolescents seeking primary and non-hospital health care must apply for benefits at local welfare agencies. This requirement has a major chilling effect on adolescents who are sick, troubled or simply fearful about applying for benefits at the welfare office.

3. Lack of Immediate Coverage

Even for adolescents who do amass the needed paper-work and make the trip to the welfare agency, the application process can be long and drawn out. At a minimum the eligibility determination process takes from 45 to 60 days, depending on the basis for which coverage is sought. It is not uncommon for eligibility determinations to take months. While reimbursement to providers can be made on a retroactive basis (and indeed can even include payment for services rendered prior to the date of

application), the absence of formal enrollment adds enormously to infected adolescents' problems in securing health care.

VII. Public Health and Prevention Strategies for Adolescents

The only solution presently available to stop this epidemic is to prevent transmission. However, our relative lack of knowledge about the lives and behaviors of adolescents further compounds the difficulties of developing effective prevention programs and messages. Disapproval of adolescent sexual experimentation and substance abuse has stifled much research in these areas. More generally, we know little about how adolescents make decisions. Of the many programs that have attempted to encourage behavioral change or health behaviors in adolescents, very few have had adequate evaluation components. We do not have the time to rediscover the same successes and to repeat our own failures. It is, therefore, crucial that resources be devoted to research into the epidemiological and behavioral aspects of HIV transmission in adolescents, as well as to the broader issues of adolescent behavior.

Nevertheless, the experience of those who have provided care, support and social services to adolescents at risk, and the research that has been done to date on adolescent behavior does provide some guidance in developing effective HIV prevention programs for adolescents. The message we send to adolescents about HIV prevention must be consistent and it must pervade their world. It is crucial that we attempt to reach adolescents at

every available opportunity -- from one-on-one encounters between providers and young people, to group programs, and to mass media campaigns. So far as we possibly can, we must seek to create a sense of a new social norm -- one that provides constant support for those who choose preventive behaviors.

There are, in fact, many opportunities to reach adolescents. Schools are an obvious but so far underutilized resource. HIV prevention education programs have been included in the required curriculum for all children and adolescents in New York State. Too frequently, however, the messages given have been imprecise, and weakened by the resistance of local school boards and local school officials. In New York State, any HIV education provided for children in kindergarten through sixth grade is carried out within the regular health curriculum, and varies widely in content and in quality. The statewide requirement for adolescents -- one semester of health education in junior high school and one in senior high school -- is clearly inadequate. HIV education must begin with education itself, must focus as early as thoughts of sexual experimentation emerge, and must be reiterated in every school year.

School programs reach only those adolescents in school. The drop out rate is frighteningly high in New York City and in New York State, and, as noted above, out-of-school youth are at highest risk. HIV prevention programs must be incorporated into youth and community programs as well as those health and social service programs that reach adolescents. Media campaigns --

including posters in the subways and on buses, and public service announcements on television and radio -- are an important way to reach those adolescents who don't come in contact with other systems. These messages will also reinforce those given in all of the in-school and out-of-school programs.

As we have learned from past efforts to reduce teen pregnancy, smoking and alcohol use, information alone does not lead to behavioral change. Programs must be carefully developed to provide adolescents with information in a form they can understand and accept, and to assist teens in developing the skills necessary to initiate and to maintain preventive behaviors. Adolescents are likely to reject HIV-specific programs; in general, providers have found that adolescents only choose to engage in programs that meet their self-defined needs and desires, ranging from food and shelter to athletics programs or art classes.

Drawing on presentations by experts on adolescents and HIV and a review of relevant literature in the field of adolescent behavior, the Committee offers the following list of characteristics that must be considered in developing programs for this age group:

1. Programs must be constructed specifically for adolescents. If they are not, the system will create programs that are most appropriate for children or for adults, and will overlook adolescents. There is a body of evidence that teens

will not avail themselves of services provided on a non-age-specific model. All programs dealing with adolescents must be developmentally appropriate and sensitive to needs as perceived by and defined by adolescents themselves.

2. In order to succeed, programs for adolescents must provide a careful balance between narrow and specific AIDS prevention and more comprehensive services and instruction. Categorical interventions that focus on a single issue such as AIDS prevention generally fail or, in the best of hands, are minimally effective on a transitory basis. Comprehensive programs that integrate a broader range of issues and focus on developing life skills, social competence and self-esteem, have been shown to be more effective. Such programs may, however, have little impact on specific AIDS prevention behaviors. Those programs that attempt to encourage development of generic and comprehensive skills within the context of a categorical domain (here AIDS) appear to have the best results. Even so, for such programs to be successful they must be implemented by well-trained staff over a substantial period of time. The impact of a one-time effort can be sustained and augmented greatly by "booster" sessions at regular intervals. Comprehensive services may also need to include food, shelter, remedial education, clothing, medical care, mental health services and employment among other supports. Programs that do not provide comprehensive services are far less likely to be effective. By addressing

adolescents' self-defined needs first, the provider can build a relationship of trust with the child which in turn acts as the basis for effective HIV prevention education. School-based health clinics that provide care for what the adolescent sees as his greatest need (such as acne) can often provide the stimulus for the adolescent to develop a relationship with the health care system.

3. Adolescent programs will be most successful if they address the adolescent in the context of his or her world:

a. Programs should use peer teaching and support to promote behavior change.

b. Parent involvement is a crucial factor. It has been shown that the extent of parent involvement depends on the quality of outreach to parents, not on the parent's own qualities. It cannot be assumed that the parent is not willing to participate or is not interested.

c. Community support is an important factor in determining the success or failure of a program.

4. Programs addressed to adolescents must be developmentally appropriate. When working with early adolescents, it is especially important that outreach and programming be geared to the adolescent's emotional and cognitive levels of development. Programs must also recognize teen sub-cultures, patterns of behavior, and conventions of social

interaction. For example, it is probably fruitless to encourage teenagers to "interview" their sexual partners about past risk behavior; they are unlikely to do it, or, if they do, it will be done ineptly with little effect.

5. Programs must also be culturally appropriate and designed with an awareness of the economic realities and constraints of adolescents' lives. The Latino community and its subparts and the African-American community may require widely different educational strategies to prevent the spread of HIV infection.

6. Testing adolescents for knowledge about HIV and HIV prevention is misleading since adolescents may not be able to recognize that they lack the skills necessary to initiate risk reduction. Adolescents may demonstrate high levels of HIV-related knowledge and strong sense of personal efficacy, or confidence in their own ability to carry out risk reduction behavior, while role-playing and other exercises demonstrate that they are actually unable to negotiate or implement such behavior.

Some professionals concerned with public policy and some parents might fear that talking openly with adolescents about sex will lead youngsters who are not developmentally ready to engage prematurely in sexual experimentation. Most experts deny the existence of this slippery slope. Most parents, when questioned;

want their children to receive education about AIDS and even about condoms.

It falls to families to inculcate particular values and social and behavioral standards. It is a public responsibility, however, to protect all teens by educating them to the dangers of HIV infection.

RECOMMENDATIONS

These recommendations will urge that a minimum of $16 million be spent over the next year to create effective strategies to prevent our youth from becoming infected with HIV. These monies will be in addition to funds necessary for effective school-based education. This is largely new money, although effective administration will recapture some funds from federal reimbursement. It must be continuing money -- expenditures will be required every year for the foreseeable future until the threat of this epidemic has passed. As we learn more about adolescents and AIDS we may need to spend more. All of the money that will be spent on prevention will be but a fraction of what will be required for treatment if prevention fails.

1. The New York State Department of Education and the New York City Board of Education should require that every school provide ongoing, frank, explicit and culturally and developmentally appropriate education on HIV infection, transmission and prevention, as part of a comprehensive program of health education and life skills training, to all children in all grades. These programs should integrate assistance from and develop outreach to parents, the community, and adolescents themselves. Schools and their supervisory agencies should report to the Governor yearly through the New York State Department of

Health on the content of these programs and on their evaluation, implementation and monitoring.

Mandatory and continuing HIV education carried out in school health education programs provides a unique opportunity to expose children and adolescents continuously to a full range of prevention education, and offer the most cost effective route for reaching the greatest number of young people. Therefore there should be developmentally appropriate modules for each grade, kindergarten through twelfth. Carefully constructed comprehensive programs can, in addition, help to develop the self-esteem and social skills needed to implement health promoting behaviors. Despite fiscal belt-tightening these budget lines should be protected.

Children begin to develop attitudes and assumptions about sex and drug use while still quite young - - education about the danger of HIV must start just as early. An HIV prevention education curriculum must be mandatory for all children in all grades, kindergarten through twelfth grade. At appropriate ages, no child should be denied frank and clear, developmentally appropriate information due to the preferences of local school officials or school boards. Parents should not be permitted to choose to withdraw their children from such classes, just as they are not allowed to forego vaccination for rubella or other preventable diseases.

HIV prevention education will not achieve a reduction in risky behaviors if it is presented in a narrow manner, isolated

from the real lives and concerns of adolescents. Categorical education, like categorical programming, is unlikely to succeed. School health education programs must deal explicitly and clearly with methods of HIV transmission and prevention, high risk and low risk behaviors, manifestations of disease, discrimination and confidentiality issues, as well as provide sources for further information on both prevention and care. Life style issues, heterosexual behavior and homosexuality must be presented in a nonjudgmental manner which focuses on risk reduction. Frankness and candor are absolutely crucial in presenting prevention education. Specifically, all students must receive explicit instruction in preventive behaviors such as the proper use of condoms. Students must be taught what condoms are and role play exercises must be used to teach how to negotiate with partners about their use. Schools should provide condoms in a confidential manner to all sexually active students. Where provision in the schools would compromise anonymity and discourage condom use, schools must devise an additional or alternative system of distribution.

School districts should look to resources both inside and outside of the schools for assistance in developing and implementing these programs. The New York City Board of Education is to be commended for its adoption of Growing Healthy, a comprehensive kindergarten through seventh grade health education curriculum, and its development of Being Healthy, a middle school curriculum. Each discusses AIDS in developmentally

appropriate ways. The State should support New York City and other local school districts to ensure that, whatever comprehensive curricula they select, sufficient and direct attention is devoted to AIDS.

The New York City Board of Education is also considering other models for adolescents that seem promising: these include development of core HIV education teams for each school, peer educators, parent training, community outreach and the development of community networks. HIV education can then draw on discussions led by peers, parents or teachers. Local community-based organizations with experience in HIV-related issues or in working with adolescents may assist both in developing programs for students and in training staff. Finally, peer support and peer education efforts offer a unique opportunity to allow teens to turn peer pressure around and provide support for each other.

Adequate training must be provided for teachers in a range of issues including HIV transmission, sexuality and substance abuse, as well as in social issues such as confidentiality and in counseling practices. The goal of training should be to "train the trainers" and establish a knowledgeable core of teachers statewide. It may be possible to append training modules to already mandated teacher training programs such as that required in the area of child abuse. All programs should be monitored and evaluated.

2. The Governor should ensure that all programs that serve adolescents who are disconnected from schools must provide HIV prevention education as an integrated part of their service delivery. The AIDS Institute should develop appropriate HIV prevention education and provide trainers for all staff in programs that serve adolescents.

A large proportion of older adolescents, variously estimated in different neighborhoods as 30-80%, are no longer in school. Some of these young adults live in areas where the prevalence of HIV infection is high, and where, therefore, sexual and drug behaviors present particular risks. These teens must be reached through programs other than school, including after-school programs, runaway shelters, Job Corps, vocational schools and training programs, family planning clinics, teen pregnancy and maternal/child health programs, STD clinics, DFY and Juvenile Justice facilities. Integrating HIV prevention education into these programs reaches the non-school population and acts to augment school-based programs.

As with school-based HIV prevention programs, outreach and youth programs must deal frankly and explicitly with all components of HIV transmission. Prevention education should include instruction in the use of condoms, social skills and interpersonal negotiation training; adolescents should have confidential access to condoms in these programs.

The AIDS Institute, with the assistance of its adolescent care and service providers, should develop training for staff

that includes HIV-specific information and sources for referral, and, in addition, develops the skills needed to work with adolescents around sensitive issues. Caregivers and service providers cannot work effectively with adolescents until they have examined their own ambivalence to adolescents and to HIV-related issues. This training is especially important for staff of DFY, of locally-operated detention facilities and runaway/homeless programs, of Department of Social Services group homes, of substance abuse treatment programs serving youth, and of institutional adolescent programs under the jurisdiction of the Office of Mental Retardation and Developmental Delay and the Office of Mental Health.

3. New York State should establish community-based comprehensive programs for those adolescents whose behaviors place them at highest risk of acquiring HIV infection, and for those adolescents who are already infected. These programs should provide developmentally appropriate HIV prevention education, confidential medical care, social services, and counselling. Programs should be designed so that adolescents can gain access to all programs and services on their own initiative and consent. New York State should allocate $12 million in 1991 to these programs.

The idea of comprehensive programs is not a new one; adolescent service providers have long recognized the utility of this design. However, agency guidelines and funding streams have

been based on a categorical approach, with each marking out its own particular territory. We must restructure funding streams so that they will facilitate, not obstruct, the development of comprehensive programs.

New York State should allocate $12 million in 1991 to the development of adolescent comprehensive programs with a commitment to ongoing funding in subsequent years. Of the approximately four million adolescents aged 10 to 24 in New York State, we estimate approximately one-half or two million engage in sexual activity or drug use that puts them at risk for infection. Five dollars per adolescent at risk is little enough to allocate to battle against HIV. Moreover, these funds will have a multiplier effect, attracting matching funds and allowing programs to draw on reimbursement from Medicaid and other sources to support ongoing service delivery.

Programs may take a variety of forms, depending on the needs of adolescents in each community. However, to reach teens successfully, these programs must be community-based, provide care in an accessible office or clinic, and be oriented specifically toward teens. They must provide services in a non-judgmental, developmentally appropriate and culturally sensitive manner and must meet the specific practical and logistical needs of adolescents, offering, for example, drop-in services and flexible hours.

Above all, programs for adolescents must be comprehensive and offer a full range of services and activities if they are to

attract adolescents. Adolescents at risk are more likely to seek services to meet their immediate needs than to seek out HIV specific programs. Even among infected adolescents, HIV cannot be treated in isolation. To an infected teen, the problems of poverty, homelessness or drug addiction may loom larger than his or her serostatus. HIV infection may also be the source of further burdens that must be addressed, including rejection by family and friends and the loss of economic support. HIV is one of a constellation of problems for adolescents; HIV-specific care must be one element in a network of solutions.

Prior evidence from adolescent programs, focused on issues such as teen pregnancy and substance abuse, demonstrate that HIV-related issues cannot be isolated from the compelling issues that influence day to day decisions made by adolescents. Comprehensive programs that address adolescents' self-defined needs and priorities provide the opportunity to develop a relationship of trust between the provider and the client and offer the only vehicle by which effective HIV prevention education can be conveyed.

Few comprehensive programs presently exist and those that do offer this integrated system of services are strained to the limits. Established clinics, community health centers, youth service providers and youth programs provide expertise for developing new programs.

New and expanded programs must be developed specifically to address the needs of gay and lesbian youth. Gay and lesbian

teens may avoid programs designed primarily for a heterosexual population out of fear of identification and rejection.

4. New York State should allocate $2 million in 1991 to develop special programs targeted to adolescents under the jurisdiction of the Division for Youth (DFY) and those adolescents who are "out-of-home" or "on the street."

The urgency of this population's need demands special focus. DFY provides services each year to over 30,000 adolescents through residential and community programs. Many of these youth are runaways, "throwaways," street kids, or other "out-of-home" youth whose drug use and sexual behaviors put them at particular risk for the transmission of HIV infection. Many will return to the street when not in DFY facilities. Street kids, who are at highest risk of infection, will not seek out services; these services, including HIV education, must be brought to them.

The Governor should allocate a minimum of $2 million per year for these youngsters who are at particularly high risk, and who are particularly vulnerable as they have few advocates and little adult support. Out of this fund, $300,000 should be allocated to provide funding for a Chief Medical Officer/Medical Director and staff for DFY in order to direct adequate HIV prevention, education and treatment efforts within that agency. The remaining $1,700,000 should be used to support, expand and replicate programs that have demonstrated success in reaching street kids and other "out-of-home" adolescents. In particular,

funds should be provided to those community-based organizations whose expertise is central to designing and expediting these programs.

5. New York State should develop adolescent-specific substance abuse treatment programs to provide access for adolescent substance abusers and substance abusing pregnant young women.

The documented links between substance abuse and HIV transmission in adolescents lend urgency to the need to provide appropriate substance abuse treatment for all adolescents, and specifically, for adolescents girls who are pregnant or who have children. There are at present virtually no available drug treatment slots for these two populations.

Opening slots for adolescents in existing drug treatment programs focused on adults is not the answer, as the needs of adolescent substance abusers differ radically from those of adults. If teens can be enticed into adult programs they are unlikely to remain. Out-patient and residential substance abuse treatment programs must be specific to adolescent needs and reflect the emotional, cognitive and developmental characteristics of adolescence.

Patterns of teen addiction today are different than in the past. Crack has had a particular appeal among teens and young adults; crack while horrendous itself also frequently leads to intravenous polydrug use and to the bartering of sex for drugs.

Adolescent mothers and pregnant teens cannot easily be integrated into existing programs. Most either do not accept these women or do not provide day care. Both the logistics and the broader issues of parenting must be incorporated into effective substance abuse treatment.

6. We make the following major recommendations for the reform of Medicaid.

a. New York State should immediately identify and review Medicaid financial eligibility and documentation requirements, modifying them as necessary to facilitate enrollment of eligible adolescents.

To the extent that the agency uses a parental income deeming definition or third party liability (TPL) identification and recovery procedures that are not compelled under federal law, those criteria should be relaxed. For example, amending the emancipated minor laws to clarify that adolescents living on their own and who are suffering from AIDS or other infectious diseases are to be considered emancipated may eliminate the state's need to comply with federal TPL disclosure rules in the case of runaways, because parents have legally been absolved of their financial liability.

b. The State should immediately establish additional convenient sites for eligibility determinations and application assistance programs at primary care settings serving adolescents at risk for or infected with HIV.

The health status of low income adolescents is so poor that all efforts should be made to reach out to teens and enroll them in Medicaid as their primary source of health care funds. But the need is particularly great in the case of teens at risk of HIV infection. The 1991 budget legislation enacted by Congress will require New York and all other states to establish convenient subsidiary programs for determining eligibility of pregnant women and children.

At each of these sites, along with other hospital and free-standing clinics serving low income teens, special eligibility assistance units should be established that assist with paperwork and applications and that offer an alternative application site. In numerous communities, the state has implemented this type of alternative entry program for pregnant women and should now do so for adolescents.

c. Presumptive eligibility for HIV-infected adolescents should be provided out of state funds.

In the case of HIV infected adolescents, there must be no delay between the time that help is sought and when it is rendered. We therefore recommend that even though no federal financial participation is available, the state establish a presumptive eligibility program that allows for the immediate issuance of Medicaid coverage. Since most of these young people ultimately will be found eligible for Medicaid, the presumptive eligibility program should be viewed simply as "a front-loading" measure, with much, if not all of, the state's initial outlay

recouped through the retroactive payment of federally matched benefits to providers.

7. The New York State Department of Health should allocate $1 million in 1991 to train providers of services and counselors to adolescents in the skills necessary to counsel adolescents about HIV testing in order to increase identification of HIV-infected individuals in this age group. These counselors must be knowledgeable about pre and post-test counseling and referrals for care and services.

The availability of prophylaxis against HIV-related opportunistic infections and early treatment for HIV illness may substantially improve the quality and length of life of HIV infected persons. It is, therefore, imperative that adolescents at high risk of exposure to the virus be provided the opportunity to be tested. While adolescents have the legal right to consent to HIV testing in New York State, providers have the ethical obligation to ensure that adolescents are tested under the following conditions: adolescents must receive developmentally appropriate pre and post-test counseling that may need to be much more elaborate than that provided to adults; the provider must determine that the adolescent has some adequate form of available support, whether a familiar adult or an identified trained provider, to help the adolescent deal with the consequences of a positive or a negative test result; providers should not offer testing unless they are able to link teens who test positive

directly with service providers. Experience indicates that it takes many more sessions to counsel adolescents than adults. A series of post-test discussions may be necessary to ensure that the youngster does not court risk behaviors, if negative, or withdraw or act out, if positive.

8. New York State should allocate a minimum of $500,000 per year to establish an "Adolescent AIDS Research Center" to collect epidemiological information necessary to improve our understanding and enhance our ability to intercept this epidemic and to gather data on the characteristics of the disease in adolescents, on adolescent behaviors which place them at risk, and on patterns of transmission in this age group.

Some characteristics of HIV among adolescents remain uncertain -- we do not know all we might about the epidemiology of HIV or the manifestations of HIV illness in adolescents. Some of the information on drug use, sexual activity and risk behavior in adolescents is anecdotal and gives rise to hypotheses that should be confirmed or refuted. Nor do we have an adequate understanding of how to influence adolescent behavior about this disease. These gaps in knowledge hamper efforts to alleviate the impact of HIV on adolescents.

At present, New York State leads the nation in gathering data on this epidemic in adolescents. If the federal government continues its present policy of underfunding research on HIV

infection, the state must continue to take the lead in this area and must either provide or secure the funds for this task.

The Adolescent AIDS Research Center should spearhead and coordinate research throughout New York State. The Governor should convene an Advisory Board on Adolescent Research to designate those areas where research is needed, to define the optimal format and location of the Center in order to assure that problems in all areas of the state are addressed, and to determine how best to structure the Center itself (perhaps as a center without walls) as well as its grants in order best to capture available matching funds from private foundations and from the federal government.

The Adolescent AIDS Research Center should fund research in the following areas:

Epidemiology: Continuing epidemiological research should document the prevalence of HIV infection and of high risk behaviors in a range of teen populations, including male and female, affluent and poor, younger and older, rural and urban, and in different ethnic and racial populations. The studies should also examine the prevalence of HIV in special populations of high risk youth, including those adolescents in locally operated, secure detention facilities and in facilities operated by DFY. Research should attempt to evaluate the relative role played by sex and drugs in HIV transmission within the adolescent population as well as between adolescents and older individuals.

Clinical Research: Research protocols should gather data on the clinical progression of the disease in adolescents. Studies should assess differences in manifestations in male and female adolescents, street kids, and adolescents infected through perinatal transmission.

Behavioral Research: Research projects should attempt to identify factors affecting adolescent decision-making, factors influencing adolescent risk perception and methods of influencing adolescents to change or modify behavior. Special attention must be paid to possible differences in developmental processes between male and female adolescents, and among adolescents from different cultural, economic and/or educational backgrounds. Particular emphasis should be placed on the issues of peer pressure and peer support, substance use, sexual experimentation and development of sexual identity and preference.

With or without the development of such a center, it is crucial that New York State make even greater efforts to publicize the results of its ongoing epidemiological surveillance, and clinical and behavioral research throughout our community. The State must educate health providers, policymakers and the public to the increasing danger that adolescents will become infected with the virus and, without intervention to modify behavior, will transmit the virus to others.

9. The Governor should initiate a private/public partnership with the business, media and advertising communities

to develop and conduct a sustained, consistent HIV prevention education campaign targeting teens.

The influence of television, radio, music videos and advertising on adolescents is staggering; unfortunately, most of the messages about sex and drugs that they receive from these sources do not advocate for safer behavior. By turning the medium around and using these channels to convey equally sophisticated messages that "sell" safe sex and safer behavior to adolescents, we can help frame adolescents' assumptions and values. Media campaigns allow us to reach those out-of-school adolescents who are hardest to reach, while reinforcing the prevention messages conveyed through schools and other programs.

While the media campaigns have been used to convey HIV prevention messages, these campaigns generally have targeted adults with messages that adolescents can all too easily dismiss as irrelevant. Materials created for adult audiences may not pierce the illusion of immortality and invulnerability so characteristic of adolescent development or provide relevant scenarios. Messages addressed to adult homosexual men may not reach adolescent males who may not acknowledge that they are experimenting with sex with men.

10. The Governor should allocate $500,000 in 1991 to create an Office of Adolescent Services directed to meld categorical funding streams into comprehensive programs, maximize funds available under matching and reimbursement formula, and

coordinate complementary and overlapping agency responsibility for adolescents.

Caregivers of adolescents testify to the confusion, chaos and frustration that surround the present fragmented system. Budgets are dauntingly complex; different funding sources require various accounting systems; permissions and approvals all demand separate applications. Comprehensive programs will be possible only if New York State creates a central authority at the State level able to coordinate existing programs, facilitate cooperation between these programs and authorize the variations necessary to present coherent services. This Office of Adolescent Services should work closely to coordinate the HIV-related activities of the New York State Department of Education, the New York City Board of Education, the range of agencies and programs serving adolescents, and the comprehensive programs and the proposed Adolescent AIDS Research Center. The office must also work to meld different funding streams, coordinate state agencies which provide categorical services to adolescents, identify overlapping programs in the New York City and New York State Departments of Health, Social Services, Mental Health, and Education, and other departments which serve or could serve adolescents. It should also provide a secure basis for existing programs and leadership for the development of new programs. This state office, if successful, could provide the model for similar local government organizations.

APPENDIX ONE
LIST OF SPEAKERS

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El Puente de Williamsburg

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Planned Parenthood of New
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Nancy Neveloff Dubler, LLB
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Mindy Fullilove, M.D.
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Beatrix A. Hamburg, M.D.
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Margaret A. Hamburg, M.D.
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Stephen Joseph, M.D.,M.P.H.
Former Commissioner of Health
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APPENDIX TWO

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